

**Sen. Gerratana and Rep. Johnson, Public Health Committee Chairmen
Sen. Welch and Rep. Srinivasan, Ranking Members**

**Testimony re: House Bill 6645,
An Act Concerning Compassionate Aid in Dying for Terminally Ill Patients
March 20, 2013**

I am testifying *not* as an advocate for one side of the assisted-suicide debate or the other. Rather, **I am here to draw public attention to a compassionate end-of-life alternative that is already and readily available for the dying.** I am testifying as a passionate advocate for hospice care, the core purpose of which is to help terminally ill patients live their remaining days – or weeks and months – with joy and dignity, and without physical or emotional suffering. I also am here as a daughter – a daughter who felt enormous gratitude, not guilt or regret, when her mother took her last breath.

My terminally ill mother wanted to live, love, and laugh until her last day on earth. So my father, my siblings and I committed ourselves to doing everything we could to help her live fully and joyfully. Nine months after her diagnosis, and following both chemotherapy for her lung cancer and radiation therapy for the multiplying tumors in her brain, my mother's disease had progressed to the point where her physician thought it made sense for us to move to hospice care, which meant, among other things, stopping further treatments designed to extend life.

It did *not* mean death was imminent; it *did* mean quality of life rather than quantity of life would be our paramount objective for the time remaining. Hospice wasn't recommended as a way to hasten death; it was recommended as a way to live life. We welcomed this.

In July 2009, hospice joined us on this quest for joyful living and peaceful dying. I am here today to tell you that hospice helped my mother and the loved ones who were caring for her achieve what we hoped for and so much more.

I do not mean to suggest that I believe hospice is, or should be, the best alternative for every patient or every family. However, I venture to guess that a relatively large percentage of those who advocate in favor of assisted suicide as *the* compassionate end-of-life option have not heard of hospice or do not understand what it is and does. Many, I assume, are in favor of assisted suicide as an option because they are afraid of suffering – either their own or a loved one's – or because they want to spare their family members the anguish and pain that comes with watching someone we love suffer.

Perhaps hearing stories like mine will help these assisted-suicide proponents understand that hospice relieves pain and suffering for the patient AND, at the same time, it wraps the despairing family in a blanket of support that makes the unbearable bearable for them, too.

My terminally ill mother died at home, at peace, with dignity, and without pain – physical *or* emotional. For three months, a hospice team that included a nurse who stayed in regular contact with Mom's primary care physician, a spiritual counselor, a social worker, a bereavement counselor, and several very special volunteers surrounded my mother and her family with love and comfort.

Reassurances from hospice that my mother's pain would be kept under control assuaged one of her biggest fears – and ours. Arguably even more important than hospice's promises about pain management, though, is the fact that hospice providers understand suffering is not just a physical phenomenon caused by symptoms of disease and pain; suffering is also caused by the existential distress one feels when experiencing fear, loss of hope, loss of dignity, loss of control. Hospice team members lovingly addressed my mother's emotional pain, which was much more intense than her physical suffering. They provided care for my mother's whole person – her body, her mind, her soul – and also for her whole family.

I do believe too few people understand what hospice is, and *too many* believe it is something it isn't.

After an op-ed I wrote on this very subject was published in the *Hartford Courant* in January, I heard from a lot of people who expressed gratitude for my having shone the light on the compassionate mission and work of hospice. But I also heard from a woman who told me about her father's excruciating pain from cancer that had metastasized to his bones; she told me of her sister's cancer and her heartbroken 10 year-old niece who witnessed her mother's suffering; she cited the high cost of healthcare and urged me to understand that "each of us has only so much money to afford extended care."

Perhaps she didn't realize hospice could have helped with her father's pain, her sister's suffering, and even her niece's heartache. Perhaps she didn't know that hospice is paid for through the Medicare Hospice Benefit, Medicaid Hospice Benefit, and most private insurers.

In closing her letter to me, the woman admonished me to "please allow each person to make the medically assisted suicide choice for themselves. One size doesn't fit all," she wrote.

I understand this. And I understand that people will and should follow their conscience when making life and death decisions. It is not my desire to render opinions about one end-of-life option being right and another wrong. I am not here to judge. I am here because I fervently hope more people facing terminal illness will make *informed* decisions – decisions that take into account *all* the options.

Ultimately I hope more people will ask for hospice or welcome it when it is suggested, understanding that it is as focused on ensuring quality of life during the final months, weeks, and days as it is on ensuring death with dignity and without pain when the end finally comes. And when it's that time, hospice represents *assisted dying*, not assisted suicide.

There arguably is no more compelling example of compassionate care in our healthcare system today than hospice. I hope more daughters, sons, husbands, wives, and parents will feel the sense of profound gratitude I experienced in the midst of my grief – gratitude for the gift of hospice, and gratitude that we had given Mom a good death. She was at peace, and so were we.

Respectfully submitted,
Linda S. Campanella

West Hartford, CT, resident and author of *When All That's Left of Me Is Love*, award-winning memoir about the joy-filled year between my mother's terminal diagnosis and her death